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Psychological aspects of hematopoietic stem cell transplantation in patients with hematological malignancies

Braamse, A.M.J.

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Summary of the main findings

Chapter 2 described the study protocol of a randomized clinical trial by means of which we examined the effectiveness of a stepped care intervention program on psychological distress and QOL in hematological cancer patients treated with auto-SCT.

In **Chapter 3**, the results of our randomized clinical trial were presented. The stepped care program as examined in this study was not effective in treating psychological distress in hematological cancer patients treated with auto-SCT. This could mainly be explained by the low uptake of the intervention, probably because of the low baseline levels of psychological distress. In addition, 10.3% of the patients in the study received psychological or psychiatric care outside of our intervention program at some point during the study period.

In **Chapter 4**, we aimed to elucidate the problem profile and care needs of patients treated with auto-SCT or allogeneic stem cell transplantation (allo-SCT). We also determined risk factors for reporting distress and/or problems after HSCT. The results showed that up to five years after auto-SCT or allo-SCT, patients continue to experience problems, mainly in the physical domain. Cognitive-emotional and practical problems were also reported, but less frequently. A minority of HSCT patients reported care needs. A risk factor for reporting distress as well as problems after auto-SCT was presence of comorbid diseases. Risk factors for reporting distress and problems after allo-SCT included younger age, shorter time after transplantation, and presence of graft-versus-host disease (GVHD).

Chapter 5 concerned an interview study with the purpose to elucidate patients' help-seeking behavior after treatment with auto-SCT. We aimed to gain more insight into the observed discrepancy that patients with auto-SCT face a life-threatening disease and stressful treatment, yet report a relatively low need for additional supportive care. The results of the study showed that patients' personal goals, future perspective, and phase of recovery determined whether patients experienced a symptom as a problem. Patients preferred to deal with problems themselves or with support from (close) relatives rather than bring in professional help. Finally, patients' appeal for professional help depended on their coping strategies, social network, and knowledge of available care.

Chapter 6 consisted of a systematic literature review on prognostic factors for QOL after HSCT. Evidence from 35 studies was reviewed. Strong evidence suggested that presence of graft-versus-host disease (GVHD) predicted worse global QOL, and that chronic GVHD predicted diminished physical well-being. Strong evidence suggested that conditioning regimen predicted neuropsychological functioning in allo-SCT patients: patients receiving myeloablative conditioning (compared with reduced intensity conditioning) showed more impairments on various neuropsychological tasks. Being female (strong evidence, mixed patient group) and receiving less social support (moderate evidence, allo-SCT patients) predicted depression; pre-transplant distress (strong evidence, mixed patient group) predicted post-transplant psychological distress. Female patients returned to work less often and later compared with male patients (mixed patient samples). Finally, in auto-SCT patients, strong evidence was found for older age predicting better social functioning.

In **Chapter 7**, we aimed to develop and test a prediction model to estimate patients' functioning after HSCT. Specifically, we examined which models could best predict physical functioning and psychological functioning in HSCT survivors, 3-10 years after transplantation.

We concluded that it is possible to predict physical and psychological functioning with readily accessible predictors. However, the accuracy of the prediction models as developed in this study needs improvement before they can be recommended for use in clinical practice. We identified younger age, higher BMI, employment status (part-time work, or no part-time or full-time work, as opposed to full-time work), more comorbid diseases, autologous transplantation, and extensive chronic GVHD were identified as predictors of physical functioning. Female gender, younger age, higher BMI, having no partner, autologous transplantation, and extensive chronic GVHD predicted psychological functioning.